Design for Health

ISSN: 2473-5132 (Print) 2473-5140 (Online) Journal homepage: http://www.tandfonline.com/loi/rfdh20

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To cite this article: Natalie W. Stephenson, Kimberly E. Todd, Daniel J. Indelicato & Stephen H. Arce (2018): Designing and developing a mobile application to prepare paediatric cancer patients for proton therapy, Design for Health, DOI: 10.1080/24735132.2018.1448618

To link to this article: https://doi.org/10.1080/24735132.2018.1448618

Published online: 26 Mar 2018.

DESIGN FOR HEALTH, 2018
https://doi.org/10.1080/24735132.2018.1448618

Routledge
Taylor & Francis Group

CASE STUDY

Designing and developing a mobile application to prepare paediatric cancer patients for proton therapy

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ABSTRACT

This case study is about Proton U, the first mobile application designed for paediatric cancer patients to learn about proton therapy. The article describes how a physician and child life specialist from a proton therapy centre partnered with professors and undergraduate students to design and develop the storybook application. The study illustrates how methods from interaction design and human-centred design were utilized to create the iOS app. The article discusses the multi-disciplinary approach to the project, including team roles and the challenges faced during development. An interactive story, told through a combination of words, images and sounds, was used to engage the senses and facilitate learning. The design team reframed the problem at the systems level and identified touchpoints in the patient's journey, which led to the creation of a suite of interrelated products. The university–community partnership was a successful collaboration that resulted in a bi-lingual mobile application for paediatric cancer patients and their family members to download and use.

ARTICLE HISTORY
Received 20 January 2018
Accepted 26 February 2018

KEYWORDS
Paediatric cancer; proton therapy; mobile application development; design education; community engagement

Introduction

This case study is about Proton U (Florida Proton Therapy Institute 2017), the first mobile application designed for paediatric cancer patients to learn about proton therapy. Since learning as a child requires more than passive transfer of knowledge, we sought to develop an app to motivate, engage and provide social interaction (Aylett 2006) to children preparing for proton therapy treatment. Furthermore, as a teaching tool, Proton U aims to increase patient empowerment. As Govender maintains (Govender et al. 2015):

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> Patient empowerment is a core principle of patient-centred care and reflects one's ability to positively affect his or her own health behaviour and health status. Empowerment interventions may enhance patients' internal locus of control, resilience, coping skills, and self-management of symptoms related to disease and therapy (p 362).

This paper explains how design thinking influenced the development of Proton U and describes how a narrative facilitates learning about proton therapy. Through interactive storytelling in a rich multimedia environment, users virtually experience the sights and sounds that they will soon experience first-hand.

Background information

Each year in the United States, an estimated 10,380 children 14 years old and younger are newly diagnosed with cancer, which is the leading cause of non-accidental death among children between 1 and 14 years old (Siegel, Miller, and Jemal 2016). Many childhood cancers are managed with chemotherapy, but most paediatric solid tumours are treated with surgery, radiation therapy or both. Surgery is the preferred treatment for localized tumours, but radiation therapy plays a critical role in managing malignancies for which curative surgery would be morbid or life-threatening. Unfortunately, radiation therapy also poses risks to healthy tissue that are of special concern in the sensitive developing tissue of children. To mitigate this problem, proton therapy represents an emerging radiotherapeutic technology that allows for more precise dose delivery, thereby reducing the radiation delivered to healthy tissue and likewise the risk of radiation therapy complications and side effects (Levin et al. 2005).

An expensive and highly specialized technology, proton therapy is available at just a few centres worldwide. The University of Florida Health Proton Therapy Institute (UFHPTI; Jacksonville, FL) opened its doors to patients in 2006 as only the fourth proton therapy centre in the United States. From its inception, one of its foremost priorities was in developing its paediatric programme, and to date they have treated children and adolescent patients from 41 states, 19 countries and 5 continents.

Children arrive at the centre shortly before their six-week treatment begins. Owing to the diversity of referring teams and sites, some families arrive with little knowledge of proton therapy, its rationale or technical delivery, which can complicate an already difficult transition of care. For these situations and more, a UFHPTI child life specialist (CLS) develops strategies to inform patients as well as reduce their anxiety and fear about proton therapy. The CLS (K. Todd) works closely with children and families to educate them on the medical procedures, helps them develop coping strategies, and provides emotional support (Scott et al. 2016). Finding that there was limited time to adequately prepare patients and families, the CLS at UFHPTI conceptualized a mobile storybook app to remotely educate children in advance of their treatment. While UFHPTI treats patients ranging in age from 18 months to 18 years, the primary target audience

for the app was children between the ages of 4 and 10 years old who might require daily anaesthesia for sedation during treatment, to prevent motion resulting from anxiety. Anaesthesia, while essential for safe and accurate radiation delivery in young children, carries the risk of unwanted side effects (Rappaport et al. 2015) and introduces complexity and additional costs to treatment (Scott et al. 2016). We hypothesized that an educational mobile app, used in combination with a CLS, could help decrease the number of children requiring anaesthesia during proton therapy, benefiting those patients as well as the greater health care system.

Studies have shown that mobile applications offer various benefits to patients, health care professionals and other stakeholders (Mosa, Yoo, and Sheets 2012; Silva et al. 2015). Mobile technology can improve service delivery and facilitate communication between patients and health care providers (Free et al. 2013). However, there is a lack of health education apps for paediatric cancer patients undergoing radiotherapy for whom only a few digital tools have been designed. The University Hospitals Birmingham NHS Foundation Trust published an animated short entitled *One of a Kind!* on YouTube ('One of a Kind! A guide to radiotherapy' 2011). In this animation, a paediatric patient, illustrated as a cartoon character, gives viewers a tour of a proton centre, showing the steps involved in preparing for and undergoing treatment. Although a commendable educational tool, it falls short of being interactive. The Children's Hospital of Philadelphia created a Prezi presentation titled *All About Proton Therapy* ('All About Proton Therapy' 2013). It includes photographs of a child undergoing proton therapy. The photographs show people, examination rooms and medical equipment, but interactivity is limited to advancing the slides and there is no audio. In summary, the lack of an app for children preparing to undergo proton therapy became an opportunity for design.

Methods

We approached this project using qualitative research methods from interaction design and human-centred design (Hanington and Martin 2012). The creative process was influenced by the five-stage model of design thinking proposed by the Hasso Plattner Institute of Design at Stanford: empathize, define, ideate, prototype and test (*An Introduction to Design Thinking: Process Guide* 2015). The design-thinking approach shifted the focus from designing products to designing experiences (Brown and Wyatt 2010). In this project, methods to empathize with users included in-depth interviews with the CLS, personas, a workshop with patients and their families and a touchstone tour at the treatment facility, which involved contextual inquiry and observation. To define the problem, we synthesized our findings from user research, reviewed field notes and photographs and analysed artefacts used by the CLS. During ideation, we generated a range of solutions to address the design challenge through group brainstorming

sessions. After selecting a design direction, we created low-fidelity prototypes (sketches, wireframes and comps) to inform the design of high-fidelity prototypes (refined interface designs built in Adobe Illustrator). A script for the storybook app was drafted, edited and finalized.

The programming language used to develop the app was C++ 11 in the Xcode 8 integrated development environment. A node-based design was used to implement individual chapters in the storyline as separate scenes, which is a modular framework that enabled varying degrees of user interaction depending on the content of the scene and simplified the adding and modifying of app content. The app was play-tested on an iPad, the iPhone 5S and the iPhone 6 as well as a Galaxy S2 before releasing through the App Store via iTunes Connect.

In addition to the primary research, secondary research focused on proton therapy, edutainment apps and designing for kids.

Participants and the project timeline

This study was a collaboration between UFHPTI, Flagler College (St. Augustine, FL) and the University of Florida (Gainesville and Jacksonville, FL). Representatives from each organization shared roles and responsibilities, such as content knowledge, interface design and app development. Multiple perspectives converged to ensure triangulation. A physician (D. Indelicato) and a CLS from UFHPTI were actively involved from inception to execution. As stakeholders in the service-learning project, they participated as co-designers and brought front-line experience into the design process (Stephenson 2016). Twenty UFHPTI patients and family members participated in generative research. Two professors and a total of 30 students from Flagler College contributed skills and knowledge from multiple disciplines. Eighteen students were from the graphic design programme. Six students in the Spanish department and an international student from Norway volunteered to translate the app's content to Spanish and Norwegian. Theatre arts students auditioned for voice acting; four were cast for voice-over roles. A communication student recorded the voice overs. Two mobile developers worked on the programming.

The university–community partnership started in 2014. Initially, the service-learning project was part of an interaction design subject offered during the fall semester of 2014. Design students in this class worked in small groups that were

Table 1. Roles and responsibilities of design team members.

	Intro, menu, Chapter 5	Chapter 1 and Chapter 3A	Chapter 2A	Chapter 4	Chapter 2B	Chapter 3B
Illustration & character design	Student 1	Student 2	[a]Student 3	Student 4	Student 5	Student 6
User experience & content development	[a]Student 7	Student 8	[a]Student 9	Student 10	[a]Student 11	Student 12
Branding & user interface design	Student 13	Student 14	Student 15	Student 16	[a]Student 17	Student 18

[a]Indicates students that participated in the project during two semesters.

formed around chapters and skills, as shown in Table 1. Depending on the task, the class could split into either six breakout groups (by chapter) to discuss specific content or into three breakout groups (by skill) to ensure a consistent style was established and applied.

At the end of the fall semester, illustrations, interface designs and branding elements had been created but needed refining. Five of the 18 design students continued working with the professor (N. Stephenson) on Proton U during the spring semester of 2015 to finalize the designs. A printed storybook and plush toys were produced in 2015. The first mobile developer started the app in 2014 and partially developed it during 2015. The second mobile developer (S. Arce) finalized programming in 2016. The free iOS app became available for download to iPads and iPhones in the Apple App Store in January 2017.

App analytics

Since the release of version 1.14 on 18 January 2017, the Proton U app has logged 233 unique sessions and has a daily average of 11 impressions in the App Store (3399 total impressions as of 30 November 2017). These values are skewed by the initial interest after the release of Proton U, though the app has consistently had at least one to two open sessions each week.

Results and discussion

The app walks users through the patient's entire therapeutic experience at UFHPTI, from check-in to treatment planning to treatment delivery. The content was derived from a PowerPoint presentation created by the CLS to pitch her idea. This pre-production storyboard outlined the product requirements but was lacking a coherent creative strategy (Lemanski 2014). Understanding that narratives have the potential to impact children because of the role that stories play in their lives and how stories can facilitate learning (Fails, Druin, and Guha 2014), we constructed a narrative to give the app a cohesive storyline.

An engaging and realistic concept

Our greatest challenge during the creative process was reaching a consensus on a narrative theme among our large design team. The first group brainstorming session yielded proposed concepts ranging from fictional to realistic. Some of the more imaginative ideas took place in adventurous settings, like a spaceship and a submarine, and featured fantastical narrators, like a talking alligator. Several of the designers were excited by the prospect of creating graphics for the fictional themes, but other designers encouraged a more empathic approach, one that would consider the child-patient's perspective. As a result, the group unified around a narrative that would not only engage children but also set realistic expectations about the experience.

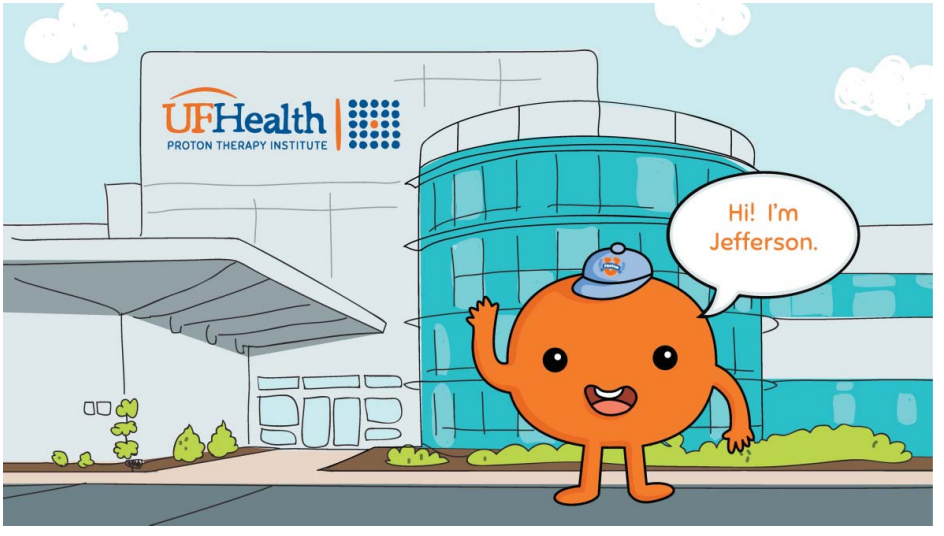

Figure 1. The sidekick character, Jefferson, is an anthropomorphic proton.

The narrative invites patients to attend Proton U, a virtual preparatory school where they learn about proton therapy at UFHPTI. The branding team designed the app icon (logo) and paired it with the tagline, 'your prep for proton therapy.' The illustration team created a cast of characters to educate and interact with users. The main characters include the CLS – also the narrator and teacher – and Jefferson – the patient's sidekick. Jefferson is an anthropomorphic proton with a caring, supportive, helpful and whimsical personality named after the street on which UFHPTI resides. We meet Jefferson when he propels from the building's signage to introduce himself. Figure 1 shows Jefferson in front of the UFHPTI building.

Table 2 describes the organization of the narrative. The content development team worked with the CLS to incorporate the required content into an original story. In conceiving the story, we considered Sarbin's definition of story as a

Table 2. How the required content was incorporated into activities in the story.

Chapters		Required content	Activities in the story
Beginning	1	Learn about the UFHPTI building	Meet Jefferson in front of the building, meet the CLS in the lobby
Middle	2	Learn about the treatment team: CLS, radiation therapist, social worker, nurse and doctor	Knock on doors to meet the other team members
	3	Learn about the CT and immobilization devices	Make a pillow and mask for Jefferson
	4	Learn about objects in the gantry	Play a matching game in the treatment room
Ending	5	Learn about the chimes in the lobby	Ring chimes to celebrate the last day of treatment, earn a certificate of completion

Note: CLS, child life specialist; CT, computed tomography; UFHPTI, University of Florida Health Proton Therapy Institute.

symbolic account of actions with a beginning, middle and an end that is held together by a plot (Sarbin 1986). In the beginning, users are welcomed to the proton centre and get to meet the medical team. In the middle, they learn about medical procedures while helping Jefferson prepare for treatment. In the end, they can ring chimes to celebrate and earn a certificate of completion.

Interactive storytelling and experiential learning

The mobile platform of the application offers the opportunity to learn through reflection on doing. As Aylett has suggested, digital storytelling gives users interactive freedom within a structured environment (Aylett 2006), allowing them the flexibility to go where they want but within a predetermined plot that indicates where they should go. To this end, the design team sought to create a balance between interaction and reflection to encourage users to pause for learning, thereby attaining with Proton U a form of experiential education. According to Kolb (2014), experiential learning is a four-stage cycle which first involves concrete learning about a new experience, followed by reflective observation, abstract conceptualization and active experimentation. With Proton U, some activities prompt users to consider a situation they will soon face and learn about it in advance. An example is the chapter in which the user helps customize an immobilization device for Jefferson. After a brief lesson on how patients are immobilized for proton therapy, the user participates as the maker of Jefferson's mask and pillow by tapping on Jefferson and other objects on the screen in a three-step process (see Figure 2). In line with edutainment, playful learning and serious games (Charsky 2010; Egenfeldt-Nielsen 2005), the interactivity adds an element of fun while demystifying proton therapy treatment.

Styled for learning styles

The content of Proton U was designed to create a multisensory experience that would appeal to the three most common learning styles: visual/spatial, auditory/

Figure 2. The process of making a pillow and mask for Jefferson.

Figure 3. The treatment team in the lobby.

verbal and kinaesthetic/tactile (Visocky O'Grady 2008). The design team considered what users would see, hear and touch when interacting with the app. Since some of the users in the target audience either cannot read or are beginning readers, and some may have vision impairments, the story is told through a combination of words, images and sounds. The diverse content that is simultaneously presented (graphics, written text and audio) was carefully developed to achieve a cohesive style. The script was written in a casual, conversational tone to portray characters as being affectively engaged with their environment. Students translated the script to Spanish and Norwegian. The illustration style was inspired by the animated works of Pendleton Ward to resemble a cartoon (McDonnell 2014). The treatment team, shown in Figure 3, is depicted as two-dimensional characters and reflect diversity in the workplace. While there's no lip syncing, the audio for each character is a recorded human voice. Voice actors were directed to sound friendly, compassionate, natural and expressive.

A system of interrelated products

By applying systems-level thinking, Proton U became more than an app. According to Jones (1992), design problems exist in a hierarchy. From bottom up are components, like logos and posters; next are products or interrelated components; and then systems or interrelated products. The design team reframed the problem at the systems level and identified touchpoints in the patient's journey. After considering this approach, the following interrelated products were created:

(1) A printed storybook that could be mailed to patients;
(2) A life-size cardboard cutout of Jefferson to welcome patients to the lobby;

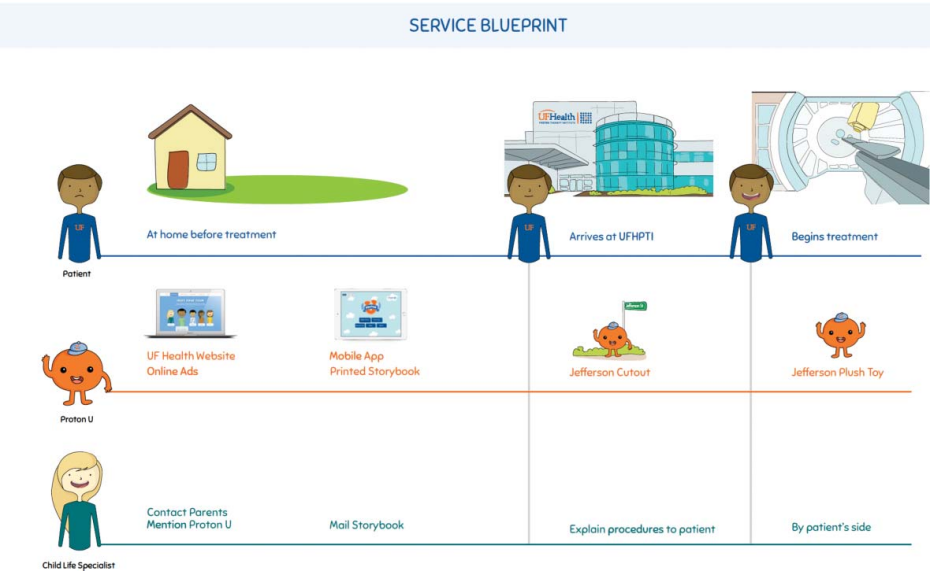

Figure 4. Service blueprint for Proton U.

(3) Proton U colouring sheets and
(4) A small, handheld plush toy of Jefferson to comfort patients during treatment.

Figure 4 shows how the products are related to patients and the CLS at each touchpoint. The diagram also visualizes how the app was implemented.

Implementing the app

There are multiple ways that patients can learn about Proton U. Some of these channels include the CLS via phone and email, the UFHPTI website and social media platforms (Facebook and Twitter), the App Store, nurse case managers and word-of-mouth from other UFHPTI patients. Patients are encouraged to download the app and play through it before arriving at the proton centre. The CLS also uses it during face-to-face sessions with patients to familiarize them with their new surroundings, especially when the gantry and CT rooms are occupied.

Shortly after the app became available, the CLS at UFHPTI began to see its direct effect on patient education. During assessments with patients, the CLS noticed that upon beginning to explain immobilization devices, patients interjected to comment on their familiarity with the process, since they had made a mask and pillow for Jefferson with Proton U. The CLS began to find that her time with patients was spent having more meaningful discussions about treatment. For example, during medical play intervention, patients who had used the app were able to re-enact exactly what they did for Jefferson. The CLS also found that questions regarding the simulation process were more informed and

nuanced. This confirms Kolb's theory on experiential learning, which states that after concrete experience and reflective observation, learners use analytical skills to conceptualize the experience.

The amount of user feedback is currently limited, but the impact thus far has been positive. The app has been well received by medical staff, patients and their family members. Future research is planned to measure the effectiveness of the app.

Conclusion

Our university–community partnership was a successful collaboration that resulted in a published mobile application for paediatric cancer patients. An interactive story was an effective way to capture users' attention and facilitate learning about proton therapy. After applying design thinking, the app became one touchpoint in a system of interrelated products.

Proton U will continue to evolve, with the goal of empowering UFHPTI patients with knowledge about their upcoming medical procedures. The app development process is ongoing, with additional features and content planned for a future release. In the next version, the team intends to add an educational game that allows users to 'zap' unhealthy cells, further emphasizing the importance of staying still during treatment, and, for younger patients, add a chapter on anaesthesia.

Acknowledgements

Special thanks to Dave Meyers, Michael Stark, María José Maguire, Heather Oakley, Amy Sapp, George Spix, the Atkinson family, the Anderson family, Stuart Klein, Nancy Mendenhall, Ronny Rotondo and Julie Bradley.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

Dr Indelicato received an educational grant from IBA.

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